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FACETS OF FAITH: SPIRITUALITY, RELIGIOSITY, AND PARENTS OF INDIVIDUALS WITH
INTELLECTUAL DISABILITY
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Abstract

Although faith has particular prominence in the contemporary American landscape, its intersection with disability and families has received little attention. We examined the spiritual and religious lives of 530 parents and caregivers of family members who have intellectual disability. For most participants, faith had clear relevance and was reflected in their congregational participation, beliefs, practices, and strength of faith. Yet considerable diversity was apparent in the ways in which each was evidenced, which included a modest number of families for whom this was not a salient aspect of their lives. Most participants identified ways in which their spirituality and religious participation contributed to their well-being. However, access to social supports through a local congregation was more muted. We address implications for professionals who support these families and congregations who welcome them. We also offer recommendations for expanding the opportunities and supports parents and caregivers need to flourish in their faith.

Keywords: religion, spirituality, severe disabilities, families, cultural competence

Facets of Faith: Spirituality, Religiosity, and

Parents of Individuals with Intellectual Disability

The place and prominence of faith within the American landscape has been studied extensively (e.g., Jones & Cox, 2017; Smith & Snell, 2009; Stausberg & Engler, 2016). The overall portrait emerging from this research indicates religion and spirituality occupy a conspicuous place in the lives of most Americans (Putnam & Campbell, 2010). According to the Pew Religious Landscape Study (2015), 77% of Americans identify with a religious tradition and almost 90% believe in God. Among those individuals who are religiously affiliated, 91% describe their faith as somewhat or very important in their lives, 89% pray at least monthly, and 62% attend religious services at least monthly. Moreover, hundreds of studies document the ways in which these priorities and practices are associated with indicators of health and well-being (Koenig, King, & Carson, 2012; Park et al., 2017).

Among parents and caregivers of the nearly 7 million Americans with intellectual disability (ID), this particular portrait is much less clear. The different facets of their faith (e.g., congregational involvement, beliefs, and practices, supports, strength of faith) have been addressed in very few studies and often only incidentally (see review by Ault, 2010). National organizations like the American Association on Intellectual and Developmental Disabilities (2015), The Arc (2010), and TASH (2010) have issued strong position statements addressing the importance of understanding and supporting this dimension of the lives of people with ID and their families. Likewise, numerous resolutions and proclamations by religious denominations have addressed why and how faith communities should be places of belonging, support, and full participation for these families (Carter, 2007). Yet, the professional literature has been taciturn about this dimension of the lives of families. Understanding the roles and relevance of faith in

the lives of parents and caregivers of family members with ID requires consideration of multiple dimensions such as: (a) congregational involvement, (b) spiritual beliefs and practices, (c) social supports, and (d) strength of religious faith.

The congregational involvement of these parents and caregivers comprise one important area of inquiry. Connections to a religious community can provide opportunities for shared spiritual practices with others who hold similar beliefs, connections to new relationships and social supports, and practical assistance offered through formal institutions. To date, the few studies addressing the religiosity of families impacted by ID have focused primarily on parents of very young children and with mixed disability samples, and have focused on how important faith was to them (e.g., Haworth, Hill, & Glidden, 1996; Rogers-Dulan, 1998; Skinner, Rodriguez, & Bailey, 1999; Weisner, Beizer, & Stolz, 1991). For example, Skinner, Correa, Skinner, and Bailey (2001) found that, among 250 parents who were of Mexican or Puerto Rican origin and had children (under age 6) with ID or developmental delay, 92% indicated they were somewhat or very religious and associated with a local church. Among 41 mothers of children (under age 12) with fragile X syndrome, Michie and Skinner (2010) found that religious faith was described as "important" or "extremely important" by 68% of participants. In their survey of 416 parents of children (primarily ages 0-30) with autism, ID, and other developmental disabilities, Ault, Collins, and Carter (2013) found that 97.6% of participants indicated their faith was important or somewhat important in their lives. However, the extent to which these parents and caregivers are involved in the array of activities offered in or through a local congregation (e.g., worship services, religious education, opportunities to serve, social events) has not been examined. In their study of 433 parents of youth (ages 13-22) with either autism or ID, Carter, Boehm, Annandale, and Taylor (2016) reported that 58% of participants attended religious

services at least weekly, 14% attended at least monthly, 16% attended at least yearly, and 12% attended less frequently or never. The extent to which mere affiliation with a congregation also entails active involvement beyond worship service attendance warrants further investigation.

The spiritual beliefs and practices of parents comprise another much-needed area of exploration. These dimensions of spirituality can impact how parents respond to disability, provide pathways for coping and family adaptation, and provide a possible source of meaning and hope. Most prior studies involving parents who have children with ID have focused more narrowly on their beliefs in relation to experiences of diagnosis and understandings of disability rather than beliefs about religion or spirituality more generally (e.g., Bennett, Deluca, & Allen, 1995; Michie & Skinner, 2010; Speraw, 2006). For example, in her qualitative interviews with 13 parents whose daughters and sons (ages 22-84) had a variety of developmental disabilities, Treloar (2002) found that the spiritual beliefs of participants gave meaning to their experience of disability, provided a source of strength, and affirmed God's purpose and plan for their lives. Likewise, Skinner and colleagues (1999) described the ways in which Latino mothers of young children (under age 6) with ID or developmental delay drew upon religious beliefs and meanings in ways that transformed their understandings of disability and themselves. Additional research should focus on the broader beliefs of parents and the ways in which practices such as prayer and meditation might be a part of their lives.

The supports parents might draw from their spirituality and religious involvement also comprises a much-needn importanted area of research (Pearce, 2005). Although the communal features of religious life could provide access to numerous social supports, this possibility has only been touched on in prior studies (e.g., German & Maisto, 1982; Reddon, McDonald, & Kysela, 1992). For example, Poston and Turnbull (2004) conducted individual and focus group

interviews with 96 parents and other caregivers of family members with disabilities (primarily under age 21). Many identified a strong spiritual component to family quality of life and highlighted the sense of strength and sense of well-being gained through social support as well as religious beliefs. Knowing more about whether and how parents and caregivers access support from their faith and congregational connections could strengthen the field's understanding of how best to further flourishing among these families.

Finally, the strength of the religious faith of parents and caregivers of individuals with intellectual disabilities is also important to understand. The strength of religious faith among parents impacted by disability has only been reported in one study—however, this study included a mixed disability sample. Specifically, Boehm, Carter, and Taylor (2015) reported higher strength of religious faith ratings among parents of transition-age youth and young adults (13-21 years) with ID or autism were associated with higher family quality of life ratings. This finding was robust even after controlling for challenging behaviors, support needs, functional abilities, and demographic factors. However, the study did not report descriptive findings for this measure. Understanding the strength of religious faith among families specifically impacted by ID could help social service professionals and religious community members more effectively support this aspect of these parents' lives.

A growing number of scholars are calling for further research aimed at elucidating the faith practices and priorities of families impacted by disability (e.g., Ault, 2010; Carter, 2013; Reynolds, Gotto, Agosta, Arnold, & Fay, 2015). The purpose of this study was to provide a multidimensional portrait of the religious and spiritual lives of parents and caregivers of individuals with ID. We addressed four research questions: (1) How involved are they in congregational activities? (2) What beliefs and practices do they report? (3) What social supports

do they draw upon? (4) How do they describe their strength of religious faith? We sought to extend the literature on this topic in several ways. First, we focused specifically on family members of individuals with ID. Most prior studies have focused on other disabilities (e.g., autism without reference to ID, chronic illness) or mixed samples. Second, we addressed a broader age span that included parents and caregivers of both children and adults. Most prior studies have focused on family members of very young or school-age children. Third, we incorporated multiple measures to address different facets of faith. Most prior studies have addressed a single dimension of spirituality or religiosity among their measures. Yet, faith is a multidimensional construct that requires consideration of multiple aspects of the lives of parents and caregivers (Fetzer Institute, 1999/2003).

Method

Participants

Participants were 530 parents (i.e., biological, step, adoptive) or primary caregivers (e.g., grandparent, sibling) of individuals with ID. To be included, participants must have been living in [removed for review]Illinois or [removed for review]Tennessee and had a child of any age diagnosed with ID. Participants ranged in age from 27.0 to 91.0 years (M = 53.3 years, SD = 11.7); the majority (90.4%) was female. About half lived in [removed for review]Illinois (51.9%); the rest lived in [removed for review]Tennessee (48.1%). Information on their relationship to the family member with ID, marital status, household size, race/ethnicity, level of education, and household income is displayed in Table 1.

Family members with ID ranged in age from younger than 1.0 through 74.0 years (M = 22.0, SD = 12.7). Over a third (35.9%) were female. About half (51.7%) of participants also reported one etiological indicator to further describe the disability; six reported two. These

indicators included Down syndrome ($n = 166$), cerebral palsy ($n = 79$), Fragile X syndrome ($n = 14$), Fetal alcohol syndrome ($n = 8$), Angelman syndrome ($n = 4$), Williams syndrome ($n = 4$), Cornelia de Lang syndrome ($n = 3$), Klinefelter syndrome ($n = 3$), Prader-Willi syndrome ($n = 2$) and one for each of Edward's, Rett, and 5p- *(cri du chat)* syndromes. Using a measure of support needs (Lee, Wehmeyer, Palmer, Soukup, & Little, 2008) across five domains (i. e., home living, community and neighborhood activities, social activities, advocacy activities, health and safety activities), parents reported their children needed the least amount of support in the area of home living activities and the most support in the area of health and safety activities. Additional demographics of family members are displayed in Table 2.

Recruitment

After receiving Institutional Review Board approval, we developed a recruitment strategy for two states— [removed for review]Tennessee and [removed for review]Illinois. We selected these states because they represented different geographical regions, provided greater diversity of religious identification and participation, and we had established connections with recruitment partners. For example, [removed for review]Tennessee ranks as the 3rd most religious state in the country and [removed for review]Illinois as the 17th least religious state (Pew Research Center, 2015). Because no statewide list of parents existed, we partnered with a wide a variety of disability- and family-focused organizations and networks who had relationships with families with members who had ID across each state. Overall, 147 partnering organizations agreed to distribute recruitment materials—about half within each state. These included disability service providers offering an array of programmatic services, educational service providers, advocacy and support providers/groups, congregation and para-congregation ministries, Arc chapters, residential service providers, parent training information centers, individuals, Special Olympics

programs, vocational service providers, medical/healthcare professionals, and other sports/recreation service providers. We provided three recruitment announcement options— email invitations, print invitations, and short newsletter or website blurbs with links to full invitations—asking partners to adapt each according to their best method for reaching parents. We followed up with each partner up to three times to ask about their recruitment efforts; 73 confirmed sending materials. We also sent 1,507 email invitations directly to parents who had participated in two prior statewide studies in [removed for review]Tennessee focused on families with a member with intellectual and developmental disabilities.

Measures

We asked participants to complete a collection of research measures addressing family quality of life, religiosity/spirituality, social relationships, stress, and demographics. The present study focuses on the sacred dimension of participants' lives: congregation involvement, religious/spiritual beliefs and practices, social supports, and strength of religious faith.

Congregation involvement. We examined congregational involvement by asking about religious affiliation, attendance at religious services, and participation in various congregational activities. For religious affiliation, we asked with which of the 39 traditions listed they most closely identified. Additional options included *other*, *I don't know*, and *I don't identify with a particular religion*. We asked how often they attended religious services: *never, less than once a year*, *once or twice a year*, *several times a year*, *once a month*, *2-3 times a month*, *about weekly*, *weekly*, or *several times a week*. We asked about the frequency of their participation in each of 13 activities taking place in or through a local congregation (e.g., attending a Sunday school or religious education class, participating in sacraments, attending congregational fellowships, potlucks, or other social gatherings; see Table 3 for items). We provided space to write in up to

two other congregational activities not already listed. Participants indicated how often they

participated in each activity: *seldom/never, several times a year, once or twice a month, at least

once a week,* or *don't know.* We selected these items from prior studies and reviews addressing

the religious involvement of individuals without disabilities (e.g., Baylor University, 2005;

Denton, Pearce, & Smith, 2008; Fetzer Institute, 1999/2003). Items in this section had good

internal consistency (Cronbach's α = .87).

      Religious/spiritual beliefs, practices, and social supports. We assessed

religious/spiritual beliefs, practices, and social supports using the Systems of Belief Inventory

(SBI-15R; Holland et al., 1998). This scale consists of two subscales (see Table 4 for items). The

Beliefs and Practices subscale consists of 10 items related to religious beliefs (e.g., "One's life

and death follows a plan from God") and practices (e.g., "I pray for help during bad times"). The

Social Support subscale consists of five items related to social support derived from a religious

or spiritual community (e.g., "I seek out people in my religious or spiritual community when I

need help"). Responses are provided on a 4-point, Likert-type scale comprised of a respondent's

level of agreement (1 = *strongly disagree*, 2 = *somewhat disagree*, 3 = *somewhat agree*, 4 =

strongly agree) or frequency of behavior (1 = *none of the time*, 2 = *a little bit of the time*, 3 = *a

good bit of the time*, 4 = *all of the time*) described in each statement. Subscale and total scores are

derived by using the overall mean for all items; higher ratings indicate greater salience of these

religious/spiritual aspects of participants' lives. The scale has strong psychometric properties

(Holland et al.) and can discriminate between religiously diverse subjects within a mixed sample

(Hall, Meador, & Koenig, 2008). Although the scale has been widely used within the healthcare

field among those with physical illness (especially cancer (e.g., Cassibba et al., 2014Hall et

al.), it hads not been used with a sample of family members of individuals with ID. We

therefore modified two questions by replacing the word "illness" with "stress" (i.e., "During

times of stress, my religious or spiritual beliefs have been strengthened" and "Prayer or

meditation has helped me cope during times of serious stress"). We made this modification

because our focus is on disability rather than healthcare and stress is therefore a more relevant

construct than illness. Among our present sample, this measure demonstrated strong internal

consistency with Cronbach's α = .96, .95, .92 for the overall score, the Beliefs and Practices

subscale, and the Social Support subscale respectively.

        Strength of Religious Faith. We assessed the strength of religious faith using the Santa

Clara Strength of Religious Faith Questionnaire – Short Form (SCSRF; Plante, Vallaeys,

Sherman, & Wallston, 2002). This scale measures a respondent's level of agreement with five

statements related to religious faith (see Table 5 for items). Responses are provided on a 4-point,

Likert-type scale ranging from 1 = *strongly disagree* to 4 = *strongly agree*. A total score is

derived by using the mean of all five items; higher scores reflect a stronger religious faith. The

original 10-item scale was developed from survey data from 102 undergraduate students (Plante

& Boccaccini, 1997). The shortened version, which we used in our study, was developed by

administering it~~the original 10-item scale~~ to a sample of 1,584 participants and selecting

questions with moderate means and high standard deviations (i.e., to avoid ceiling and floor

effects), as well as high correlations ($r > .95$; $p < .01$) with the overall score (Plante et al.). Two

studies using this shortened version reported strong internal consistency (Cronbach α = .95 and

.93) with exploratory and confirmatory factor analyses confirming a stable one-factor structure

(Storch, Roberti, Bagner, et al., 2004; Storch, Roberti, Bravata, & Storch, 2004). Additionally,

these two studies each reported convergent validity, with significant correlations with the three

subscales of the Duke Religion Index (Koenig & Büssing, 2010). Test-retest reliability with 19

participants showed a high degree of consistency with a two-week delay between tests ($r = 0.97$, $p < .001$; Storch, Roberti, Bagner, et al.). Because our study involved participants from multiple faith traditions, we substituted the word "congregation" for "church" in 1 item. For the 530 participants in the present study, overall Cronbach's alpha was .94.

Data Collection

We asked participants to complete all study measures online (professional Survey Monkey account) or using a 16-page printed version (by request). All participants were entered into a random drawing to receive one of forty $25 USD gift cards. We piloted all measures with a sample of 7 parents from both states whose child with ID ranged from 7 to 42 years asking for feedback on the content, clarity, and length. These parents offered recommendations for minor wording changes to increase the clarity of the measures. Although the overarching project included a broader set of measures, study participants must have responded to the question about frequency of congregation attendance to be included in the present analyses.

Data Analysis

We used descriptive statistics (i.e., mean, frequency, percentage) to summarize all ratings by overall scale, individual items, and subscales for congregation attendance and participation ratings (Question 1), religious /spiritual beliefs and practices ratings (Question 2), social support ratings (Question 3), and strength of religious faith ratings (Question 4). In addition, we examined the intercorrelations between all religiosity/spirituality variables as well as the extent to which these measures were correlated with the following variables: age of their daughter or son, challenging behaviors, and disability severity. Overall severity was determined by asking parents to describe their child's disability as either mild, moderate, severe, or very severe (cf., Hu, Wang, & Fei, 2012). We measured challenging behaviors ~~with~~ by adding the Behavior

Problems subscale of the Scales of Independent Behaviors—Revised (Bruininks, Woodcock,

Weatherman, & Hill, 1996) to the collection of study measures.

Results

Congregation Involvement

Most participants (90.8%) identified with a particular religion, 8.3% said they did not

identify with a particular religion, and 0.9% indicated they did not know. Among the 36 religious

affiliations represented in this sample, the most common were Catholic/Roman Catholic

(18.0%), Baptist (14.7%), non-denominational Christian (13.5%), Methodist (8.4%), Lutheran

(4.7%), and Presbyterian (4.7%), Church of Christ (3.6%), Bible Church (2.4%), Episcopal

(1.7%), Jewish (1.7%), and Pentecostal (1.7%). A small percentage (2.7%) reported their

affiliation as *Other.* Participants reported attending their congregation from 0-80 years with a

mean of 13.9 years (SD = 14.4). Specifically, the number of years parents reported being

involved in their congregation included: zero (8.9%), one (7.0%), two (6.3%), three (6.3%), four

(4.6%), five (5.5%), six to ten (16.1%), eleven to fifteen (11.6%), sixteen to twenty (10.8%),

twenty-one to thirty (13.0%), thirty-one to forty (4.1%), forty-one to fifty (2.4%), and over fifty

(3.4%). One hundred and fifteen parents (21.7%) did not provide information on how long they

had attended a congregation.

Frequency of congregation attendance varied widely across participants. Specifically,

participants reported attending religious services: *never* (11.1%), *less than once a year* (9.2%),

once or twice a year (7.7%), *several times a year* (11.5%), *once a month* (4.5%), *2-3 times a

month* (9.8%), *about weekly* (8.1%), *weekly* (28.3%), and *several times a week* (9.6%).

Frequency of congregation attendance was not significantly correlated with their child's age,

disability severity, or challenging behaviors.

Congregation participation—the extent to which participants took part in various congregational activities—is summarized in Table 3, arranged from most to least common based on involvement at least once a week. Almost two thirds of participants (70.2%) reported participating in at least one of the 13 other congregational activities in the last year. On average, participants took part in 1.5 (SD = 2.1) of the 13 activities at least once or twice a month and 3.1 (SD = 3.1) of the 13 activities at least several times a year. The most common activities participants took part in at least several times a year included: participating in sacraments (56.3%); attending congregational fellowships, potlucks, and other social gatherings (49.4%); participating in prayer, study, or small group (42.7%); attending a Sunday school or religious education class (37.9%); and participating in local outreach activities (37.9%).

Religious/Spiritual Beliefs and Practices

Participants reported overall agreement (M = 3.24, SD = 0.79) with items related to their religious/spiritual beliefs and practices (see Table 4 for individual items). More than three quarters of participants somewhat agreed or strongly agreed they feel certain that God in some form exists (91.9%); they have experienced peace of mind through their prayers and meditation (84.3%); they have experienced a sense of hope as a result of their religious or spiritual beliefs (82.9%); one's life and death follows a plan from God (81.7%); they pray for help during bad times (78.4%); religion is important in their day-to-day life (78.2%); during times of stress, their religious or spiritual beliefs have been strengthened (79.0%); and they believe God protects them from harm (75.4%). Beliefs and practices were not correlated with measures of child age, disability severity, or challenging behaviors.

Social Supports

Participants reported somewhat lower levels of agreement (M = 2.69, SD = 0.92) with

items related to social supports (see Table 4 for individual items). For example, 72.9% somewhat or strongly agreed that they enjoyed attending religious functions hold by their religious or spiritual group, but only 35.5% somewhat or strongly agreed that they seek out people in their religious or spiritual community when they need help. Lower ratings of religious/spiritual social support were significantly associated with greater disability severity ratings ($r = -.10$, $p = .01$) and ratings of more challenging behaviors ($r = .12$, $p = .02$).

Strength of Religious Faith

Participants reported overall agreement ($M = 3.01$, $SD = 0.89$) with strength of religious faith items (see Table 5 for individual items). Most participants agreed or strongly agreed they enjoy being around others who share their faith (81.9%), they look to their faith as providing meaning and purpose in their life (80.8%), their faith impacts many of their decisions (77.2%), they pray daily (73.1%), and they consider themselves to be active in their faith or congregation (59.8%). Strength of religious faith was not significantly correlated with their child's age, disability severity, or challenging behaviors.

Religiosity/Spirituality Intercorrelations

All religiosity/spirituality variables were significantly and positively correlated with each other (see Table 6). The strongest correlations included strength of religious faith with beliefs and practices ($r = 0.85$) and strength of religious faith with social support ($r = 0.80$). All intercorrelations ranged from rs = 0.37 to 0.85 ($p < .01$).

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Discussion

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Supporting parents and other caregivers to thrive in *all* aspects of their lives is affirmed in both contemporary policy and recommended practices (e.g., Reynolds & Kardell, 2017; Reynolds et al., 2015; Schippers, Zuna, & Brown, 2015). Moreover, the ordinary experiences,

supports, and relationships that enable any family to flourish are likely to be equally important to parents whose daughters and sons have an ID. The present study focused on the religious and spiritual lives of more than 500 of these parents. Our findings provide a multifaceted portrait of their congregational involvement, religious faith, beliefs, and social supports.

First, religion and spirituality held a prominent place in the lives of most of these parents and caregivers. For example, nearly 90% of participants had attended religious services at a local congregation, their involvement extended to an average of three other congregational activities, 92% affirmed the existence of God in some form, most said they prayed or meditated, and their strength of religious faith was found to be moderately strong. This portrait indicates that faith can be a very salient aspect of the lives of many parents and caregivers (e.g., Ault et al., 2013; Boehm et al., 2015; Poston & Turnbull, 2004; Rogers-Dulan, 1998; Skinner et al., 1999). They extend prior research by addressing together the multiple facets of faith in the lives of these parents to provide a fuller portrait of its place and prominence. Such findings might be considered unsurprising in light of the prevailing religious landscape within the United States (e.g., Jones & Cox, 2017; Pew Research Center, 2015). Yet they stand out in light of the limited attention that has been given to this aspect of the lives of parents within the professional literature (Ault, 2010; Carter, 2013).

Second, the portrait of these parents was also marked by considerable diversity. Participants varied widely in their frequency of religious service attendance, in the combination and number of congregational activities they accessed, in the particular beliefs they espoused, in the traditions and denominations with which they affiliated, and in the social supports they utilized. This diversity also includes a modest proportion of participants who did not consider religion and spirituality to be relevant aspects of their lives. As is evident in other spheres of life

(cf., Blustein, Carter, & McMillan, 2016; Jones & Gallus, 2016), the experiences and priorities of parents who have children with ID are not homogenous. Indeed, the specific ways in which faith was woven into their lives looked somewhat different for every participant in this study. Such diversity accentuates the importance of understanding the priorities and participation of each person rather than making advance presumptions.

Third, spirituality and religious participation may contribute to the well-being of these parents and caregivers. In our sample, 83% of participants said they experienced a sense of hope as a result of their beliefs, 73% reported that prayer or meditation helped them cope in times of stress, and 84% indicated these same practices brought them peace of mind. Such findings are consistent with a much larger literature documenting links between spirituality and well-being among people without disabilities (Koenig et al., 2012; Park et al., 2017). Access to social support through one's faith community, however, was more muted. Less than two thirds (64%) of parents knew someone in their religious or spirituality community they could turn to and only one third (35%) reported seeking out people in their religious or spiritual community when they needed help. It is unclear whether such support was unavailable, considered unhelpful, or not pursued at all by participants.

Fourth, the relevance of faith to so many parents could have implications for professionals who work closely with families. More than three quarters (77%) of parents indicated their faith impacts their decisions and many said they found emotional or social support through their spiritual practices or congregational community. Understanding the values, beliefs, sources of strength, and community connections of families is crucial to providing culturally competent services and family-centered supports (Gaventa, 2018; The Joint Commission, 2010). Asking good questions at appropriate times can provide professionals with important insight into

the salience of spirituality to a particular family and its relevance to service delivery (Carter, in

press). For some professionals, this may involve listening informally as families share their

stories and circumstances, noticing references to spiritual interests and congregational questions,

and following up with relevant questions. For others, it may involve incorporating more formal

questions about spiritual beliefs and support systems into care. Multiple tools developed in the

fields of health care, rehabilitation, and social work could be used to guide these conversations

(e.g., Gaventa, 2016; Lu, Lo, Bang, & Romero, in press; Oxhandler & Pargament, 2014).

Fifth, greater engagement of faith communities may be needed to support the spiritual

and religious lives of these families. Although attendance at religious services was fairly

prominent, considerably fewer (less than half) parents reported regular involvement in religious

education classes, small groups, or service opportunities. Such congregational activities can

provide rich contexts for developing supportive relationships, strengthening one's faith, and

accessing additional supports. Descriptive studies suggest congregations can be uneven in the

invitations and supports they extend to families with members who have ID (e.g., Amado,

Degrande, Boice, & Hutcheson, 2012; Ault et al., 2013; Carter, Boehm, Annadale, & Taylor,

2016). Likewise, studies of theological schools suggest many clergy leave their formative

training poorly prepared to meet the needs of families (Anderson, 2003; Annandale & Carter,

2014). Professionals working within disability fields could be a source of much-needed

guidance, resources, and encouragement to faith communities on how best to support families

already in their midst.

Limitations and Future Research

Several limitations suggest avenues for future research. First, we did not ask parents

about their desired degree of participation in congregational activities. As a result, we cannot

conclude whether the portrait of participation revealed in this study is encouraging or

concerning. The absence of invitations, hospitality, supports, and accessible programming have

all been cited as potential barriers to congregational involvement (e.g., Jacober, 2010; O'Hanlon,

2013). Future researchers ~~c~~should incorporate individual interviews with parents ~~in order~~ as one

way to examine the gap between desired and actual spiritual expressions and participation.

Second, our sample was restricted to just two areas of the country— ~~[removed for review]~~Illinois

and ~~[removed for review]~~Tennessee. Although we selected states that differed in a variety of

ways (e.g., economically, culturally, religiously), other regions of the country may differ

substantially in their religious and spiritual priorities. The heterogeneous religious landscape of

the United States highlights the importance of recruiting national samples in future studies

addressing the experiences of families. One approach for accomplishing this work more

efficiently would be to incorporate relevant disability variables into recurring studies (e.g.,

Gallup, Pew). Third, our findings reflect the views of just one member of each household; most

often the mother. It is unclear whether the beliefs, religious faith, and spiritual practices

expressed by these parents are shared by others in their immediate families. For example, among

the 75% of participants who were married, future studies could address the extent to which both

parents converge or diverge in their views (cf., Biesenger & Arikawa, 2007: Haworth et al.,

1996). Fourth, the voluntary nature of this study may have meant some parents and caregivers

selected in or out on the basis of its focus. Although we emphasized in our study invitations that

we wanted to hear from individuals for whom spirituality and religion was and was not relevant,

the sample could have been biased. Future studies should address whether the portrait of parents

may be even more heterogenous that was reflected in our sample. Fifth, we did not examine the

ways in which the spiritual and religious lives of parents impacted the spiritual and religious

formation of their children with ID. Numerous studies have documented the shaping influence of parents on the beliefs and practices of their children without disabilities (e.g., Barry, Nelson, Davarya, & Urry, 2010——). Future researchers should examine the ways in which this dimension of parents' lives impact the upbringing, experiences, and perspectives of their daughters and sons with ID.

Conclusion

Faith can be a relevant and prominent aspect of the lives of parents and caregivers whose family members have ID. Yet the diversity reflected in our findings provides an important reminder that individualization must always mark efforts to support the spiritual and religious lives of these families. Understanding the preferences and practices of individuals in this area can ensure services and supports are designed in ways that align with their priorities and needs.

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Table 1
Demographics of Responding Participants

Variable	*n*	%
Relationship to family member with ID		
Mother	455	86.0
Father	45	8.5
Sibling	14	2.6
Grandparent	8	1.5
Aunt/Uncle	2	0.4
Other (i.e., cousin, foster, guardian)	5	0.9
Information not provided	1	
Marital status		
Married	404	76.5
Living as married	9	1.7
Separated or divorced	59	11.2
Widowed	30	5.7
Single (not married or living together)	26	4.9
Information not provided	2	
Household size		
Living alone	15	2.8
Two	96	18.1
Three	164	31.0
Four	144	27.2
Five	66	12.5
Six or more	42	8.3
Information not provided	1	
Race/ethnicity[a]		
White (non-Hispanic)	463	86.5
African American/Black	41	7.7
Latina/Latino/ Hispanic	17	3.2
Asian/Asian American	10	1.9
American Indian or Alaska Native	2	0.4
Other (e.g., Middle Eastern)	2	0.4
Information not provided	1	
Highest level of education completed		
Some high school	2	0.4
High school degree	47	8.9
Some college	102	19.2
Two-year degree	56	10.6
Four-year degree	160	30.2
Graduate/professional degree	163	30.8
Annual household income		
Less than $15,000	14	2.8
$15,000 – $34,999	71	14.1
$35,000 – $49,999	57	11.3
$50,000 – $74,999	106	21.0
$75,000 – $99,999	85	16.8
$100,000 or more	172	34.1
Information not provided	25	

Note. Percentages are based on the number of participants who completed the given item.
[a]Response instructions included *check all that apply;* thus total is more than 100%.

Table 2
Demographics of Family Member with Intellectual Disability

Variable	*n*	%
Gender		
Female	188	35.9
Male	336	64.1
Information not provided	6	
Age		
Birth to 9	86	16.2
10 to 19	158	29.8
20 to 29	156	29.4
30 to 39	76	14.3
40 to 49	38	7.2
50 or above	16	3.0
Additional autism spectrum disorder (ASD) diagnosis		
Yes	216	40.8
No	313	59.2
Information not provided	1	
Perceived disability severity		
Mild	74	14.0
Moderate	290	54.7
Severe	134	25.3
Very severe	32	6.0
Level of seriousness of behaviors[a]		
Normal	295	61.5
Marginally serious	84	17.5
Moderately serious	49	10.2
Serious	36	7.5
Very serious	16	3.3
Information on all items not provided	50	

Note. Percentages are based on number of participants who completed the given item.
[a]Behavior Problems subscale of the Scales of Independent Behaviors—Revised.

Table 3
Frequency of Participation in Various Congregational Activities

Activity	Missing	Seldom/ never	Several times a year	Once or twice a month	At least once a week	Don't know
Attending a Sunday school or religious education class	21	61.3	10.2	5.9	21.8	0.8
Participating in prayer, study, or small group	19	56.4	15.5	9.2	18.0	1.0
Participating in sacraments (e.g., communion, confession, anointing)	22	42.1	19.9	22.2	14.2	1.6
Participating in prayer meetings	24	68.2	13.8	5.5	10.9	1.6
Serving in the choir or on a music team	25	88.3	3.8	1.8	5.0	1.2
Participating in local outreach activities (e.g., serving a community center, visiting shut-ins)	19	60.7	26.0	7.4	4.5	1.4
Attending congregational fellowships, potlucks, and other social gatherings	21	48.5	36.1	10.2	3.1	2.0
Leading prayers publicly during religious services	26	87.9	6.3	3.4	1.4	1.0
Leading scripture readings during religious services	24	89.1	5.9	2.8	1.4	0.8
Attending a religious retreat, conference, rally, or congress	20	81.4	14.9	1.2	1.4	1.2
Serving as an usher or greeter	23	87.0	6.5	4.1	1.2	1.2
Serving as an acolyte or alter server	31	95.6	1.6	0.8	1.2	0.8
Participating in a national or international mission activities (e.g., short-term trips)	29	91.4	5.2	1.6	0.2	1.6
Performing other forms of service for the congregation (write in): _____	157	61.1	12.9	12.1	7.8	6.2
Participating in other congregational activities (write in): _____	217	71.2	7.3	7.3	3.2	10.9

Note. *n* = 530. Missing column represents the number of people with missing data on that item. Percentages of responses are based on the number of participants completing a given item.

Table 4
Parent Responses on System of Belief Inventory (SBI-15R) Scale Items

| Subscale/Item | Missing | Percentage of responses | | | | *M* (*SD*) |
		Strongly Disagree (1)	Somewhat Disagree (2)	Somewhat Agree (3)	Strongly Agree (4)	
Beliefs and practices						
I feel certain that God in some form exists.	3	4.0	4.2	10.1	81.8	3.70 (0.73)
One's life and death follows a plan from God.	6	9.9	8.4	24.8	56.9	3.29 (0.98)
I have experienced a sense of hope as a result of my religious or spiritual beliefs.	3	10.2	6.8	27.3	55.6	3.28 (0.98)
I pray for help during bad times.	2	8.1	13.4	24.8	53.6	3.24 (0.97)
I have experienced peace of mind through my prayers and meditation.	2	8.9	6.8	36.4	47.9	3.23 (0.92)
Religion is important in my day-to-day life.	1	15.3	6.4	23.8	54.4	3.17 (1.09)
During times of stress, my religious or spiritual beliefs have been strengthened.	5	9.9	11.0	32.0	47.0	3.16 (0.98)
I believe God will not give me a burden I cannot carry.	8	14.6	11.3	23.6	50.6	3.10 (1.09)
Prayer or meditation has helped me cope during times of stress.	2	8.1	18.4	31.3	42.2	3.08 (0.96)
I believe God protects me from harm.	6	12.0	12.6	32.3	43.1	3.06 (1.02)
Social support						
I enjoy attending religious functions held by my religious or spiritual group.	6	15.1	12.0	33.2	39.7	2.98 (1.06)
I enjoy meeting or talking often with people who share my religious or spiritual beliefs.	4	11.4	28.1	28.5	31.9	2.81 (1.01)
When I need suggestions on how to deal with problems, I know someone in my religious or spiritual community that I can turn to.	2	24.1	11.6	31.4	33.0	2.73 (1.16)
When I feel lonely, I rely on people who share my spiritual or religious beliefs for support.	4	19.0	18.1	34.8	28.1	2.72 (1.07)
I seek out people in my religious or spiritual community when I need help.	3	32.6	31.9	21.8	13.7	2.17 (1.03)

Note. *n* = 530. Missing column represents the number of people with missing data on that item. Percentages of responses are based on the number of participants completing a given item.

Table 5
Parent Responses on Santa Clara Strength of Religious Faith Questionnaire – Short Form

Item	Missing	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)	*M* (*SD*)
		Percentage of responses				
I look to my faith as providing meaning and purpose in my life.	5	10.5	8.8	36.4	44.4	3.15 (0.96)
I enjoy being around others who share my faith.	6	8.6	9.5	46.4	35.5	3.09 (0.89)
My faith impacts many of my decisions.	3	10.2	12.5	38.3	38.9	3.06 (0.96)
I pray daily.	6	11.8	15.1	32.6	40.5	3.02 (1.02)
I consider myself to be active in my faith or congregation.	6	16.2	24.0	29.8	30.0	2.73 (1.06)

Note. $n = 530$. Response options reflect level of agreement ranging from 1 = *strongly disagree* to 4 = *strongly agree*. Percentages are based on the number of participants who completed the given item.

Table 6

Intercorrelation Matrix for All Religiosity/Spirituality Variables

Variable	1	2	3	4	5
1. Frequency of congregation attendance	–				
2. Number of congregational activities (at least monthly)	.64** (530)	–			
3. Beliefs and practices	.62** (509)	.37** (509)	–		
4. Social support	.76** (518)	.54** (518)	.75** (500)	–	
5. Strength of religious faith	.74** (517)	.50** (517)	.85** (500)	.80** (509)	–

Note. Number in parenthesis = *n*.
** *p* < .01.